

Summary Information sheet

In this research study we will use information from your health records which is collected as part of the NHS Breast Cancer Screening Program. We will only use information that we need for the research study. The research will involve removing information which can identify you such as your date of birth before being used in the study but will involve looking at things such as whether you attended your smear test.

Organisations that have access and a legal basis to hold your data only such as NHS England will be able to access your personal data. All parties involved will follow all privacy rules.

At the end of the study we will save some of the data in case we need to check it. We will make sure no-one can work out who you are from the reports we write.

This notice informs you further about what is involved.

HOW WILL WE USE INFORMATION ABOUT YOU?

Research Study Title:

Investigating the use of image interventions alongside usual invitations to facilitate attendance at Breast Cancer Screening

Summary sheet

Imperial College London is the sponsor for this study and will act as the data processor for this study. This means that we are responsible for looking after your information and using it properly. Imperial College London will keep your personal data for:

- 10 years after the study has finished in relation to data subject consent forms.
- 10 years after the study has completed in relation to primary research data.

WHAT IS INVOLVED?

This study is looking to explore the effect of different communication sent by breast cancer screening services in 2024 to invite people to breast cancer screening. To help improve attendance at breast cancer screening we need to understand whether people attended their screening, which message worked best, and whether people from different backgrounds attended screening.

We are looking to use this data to answer these important questions, by using information from records of people who were invited to screen in Surrey between 09/24 and 03/24. To do this we will be looking at information that is routinely collected by the breast cancer screening service, who organise NHS breast Screening.

We will need to use information from your health records for this research project, which are taken from NHS England, and not hospitals.

WHAT DATA WILL BE USED?

The information we will use will include your data about you (ethnicity, age), about your previous screening (whether you attended your last screening). The information researchers see will not contain personal identifiers (e.g. NHS number or postcode).

Instead we are asking organizations that keep personal health information as part of their normal duties in the health of the public to collect this data. They will then remove anything that can identify an individual directly (e.g. your date of birth). This organization is the NHS Breast cancer screening service (the direct care team) who are involved in screening invitations. You will not be asked to provide any further information. NHS Breast Cancer Screening Service will keep a record temporarily of what information is involved, so that if you wish to have your information removed you can do so by contacting them. People will use this information to do the research to make sure that the research is being done properly. We will keep all information about you safe and secure.

Once we have finished the study, we will keep some of the data so we can check the results but this will not be able to identify individuals (so called anonymization). We will write our reports in a way that no-one can work out that you took part in the study.

LEGAL BASIS

As a university we use information to conduct research to improve health, care and services. As a publicly-funded organisation, we have to ensure that it is in the public interest when we use information in research. For this study, researchers will **not** be able to view your personally-identifiable data. Instead NHS Breast Cancer Screening Service that already possess this data for their regular purpose will be asked to extract it, in such a way that it cannot be directly used to identify you. This will be before they allow us to use your data in research.

Health and care research should serve the public interest, which means that we have to demonstrate that our research serves the interests of society as a whole. We do this by following the [UK Policy Framework for Health and Social Care Research](#). Further details regarding this process is available from NHS Digital <https://digital.nhs.uk/about-nhs-digital/our-work/keeping-patient-data-safe/how-we-look-after-your-health-and-care-information/your-information-choices/opting-out-of-sharing-your-confidential-patient-information>

INTERNATIONAL TRANSFERS

There may be a requirement to transfer information to countries outside the European Economic Area (for example, to a research partner). Where this information contains your personal data, Imperial College London will ensure that it is transferred in accordance with data protection legislation. If the data is transferred to a country which is not subject to a European Commission (EC) adequacy decision in respect of its data protection standards, Imperial College London will enter into a data sharing agreement with the recipient organisation that incorporates EC approved standard contractual clauses that safeguard how your personal data is processed.

SHARING YOUR INFORMATION WITH OTHERS

For the purposes referred to in this privacy notice and relying on the bases for processing as set out above, we will share your personal data with certain third parties.

- NHS England already possess identifiable data as part of their role in public health. More information on this organisation and how they use data in research can be found at the following links:
 1. <https://www.gov.uk/government/publications/accessing-public-health-england-data/about-the-phe-odr-and-accessing-data#data-release-register>
 2. <https://digital.nhs.uk/about-nhs-digital/our-work/keeping-patient-data-safe/how-we-look-after-your-health-and-care-information/your-information-choices/opting-out-of-sharing-your-confidential-patient-information>
- Other College employees, agents, contractors and service providers (for example, suppliers of printing and mailing services, email communication services or web services, or suppliers who help us carry out any of the activities described above). Our third party service providers are required to enter into data processing agreements with us. We only permit them to process your personal data for specified purposes and in accordance with our policies.

WHAT ARE YOUR CHOICES ABOUT HOW YOUR INFORMATION IS USED?

You can request for your data to be removed for research purposes from NHS England at the above weblinks, this is called an 'opt-out' procedure. To opt-out you **do not need** to give a reason. There are two ways you can opt-out.

1. If you choose, you can ask for your data not to be used in *any* research of this kind from now on. This is through NHS Digital's Type 2 opt-out mechanism at link 2 above. Here you will be able to ensure your data is not used for any research, **including** the study we are undertaking. The opt-out will **not** affect your medical care or if your doctor needs to share information important for your health.

2. If you choose, you can ask for your data not to be used in *this* research study specifically. To do this you will need to contact researchers via one of the methods listed below. The researchers will help you with the process which will involve contacting the person responsible for the data transfer at NHS England, depending on when in the study you request the opt-out. That person will remove your data, so it is not transferred, and confirm this with you. Please note that once NHS England have completed the transfer process and removed anything that can be identified, it will not be possible to remove individual records. You can, however, still exercise your right for national opt-outs. Also be aware that your data will be available for other researchers and similar projects to use.

WHERE CAN YOU FIND OUT MORE ABOUT HOW YOUR INFORMATION IS USED OR DISCUSS OPT-OUT

You can find out more about how we use your information

- at www.hra.nhs.uk/information-about-patients/
- by asking one of the research team
- by sending an email to Ada Humphrey (a.humphrey@ic.ac.uk) or
- by ringing us on +44 (0)20 7589 5111

COMPLAINT

If you wish to raise a complaint on how we have handled your data, please contact Imperial College London's Data Protection Officer via email at dpo@imperial.ac.uk, via telephone on 020 7594 3502 and/or via post at Imperial College London, Data Protection Officer, Faculty Building Level 4, London SW7 2AZ.

If you are not satisfied with our response or believe we are processing your personal data in a way that is not lawful you can complain to the Information Commissioner's Office (ICO). The ICO does recommend that you seek to resolve matters with the data controller (us) first before involving the regulator.